

Chapter 3

Internet–Based Chronic Disease Self–Management for Youth

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ABSTRACT

Chronic health conditions in children and youth are important health problems that seriously affect all aspects of their everyday lives. There is growing recognition of the need to promote disease self-management in youth with chronic health conditions. While there is evidence of the effectiveness of self-management programs to improve health outcomes in pediatric chronic illnesses, there are barriers to youth receiving these services. Internet-based programs offer an innovative approach to improve the availability, accessibility, and acceptability of these programs. This chapter provides an overview of Internet-based chronic disease self-management treatment programs for children and youth. It defines and describes the underlying theories, processes, and content elements of Internet-based self-management programs. Practical tips for program development and evaluation in terms of improved health outcomes are also discussed based on the authors' experience with developing the "Teens Taking Charge: Managing Arthritis Online" self-management program for adolescents with arthritis. Future directions for theory, research, and clinical practice are also described.

INTRODUCTION

Despite the focus on chronic disease self-management in adults; little attention has been directed to promoting disease self-management in children and youth with chronic health conditions. It is

estimated that 10-15% of children and adolescents have significant ongoing health care needs related to chronic health conditions that will persist into adulthood (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Childhood chronic illness can negatively impact all aspects of health-related quality of life and also have a significant

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economic impact on the health care system and families (Barlow & Ellard, 2006; Bernatasky et al., 2007; Newacheck, Inkelas, & Kim, 2004; Shaw, Southwood, Duffy, & McDonough, 2006; Turkel & Pao, 2007). Disease course can be unpredictable and children commonly experience a myriad of symptoms that restrict physical and social interactions (Barlow & Ellard, 2006; Shaw et al., 2006; Turkel & Pao, 2007). Disease management is often complex, involving multiple therapies over long periods of time that require frequent monitoring. In the absence of cure, improving health-related quality of life through better disease self-management becomes critical (Phelps, 2006). While there is evidence of the effectiveness of self-management programs improving health outcomes in children (e.g., asthma and diabetes), many youth with chronic health conditions do not receive comprehensive disease education with self-management strategies and meaningful social support (Barlow & Ellard, 2006; Barlow, Shaw, & Southwood, 1998; Smith et al., 2005). The Internet is a widely available, affordable, and interactive medium that is well suited to teaching disease self-management skills and can easily address barriers such as inaccessibility and unavailability. From a public health perspective, there is much potential for self-administered treatments to improve the health of children who suffer from chronic illnesses but are unable to access services.

BACKGROUND

Self-management can be defined as “the individual’s ability to manage the symptoms, treatment, physical and psychological consequences, and life style changes inherent in living with a chronic illness” (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, pp.178). It is a dynamic and continuous process of self-regulation that encompasses the ability to monitor one’s health condition and to carry out the cognitive, behavioural and emotional responses necessary to maintain a

satisfactory quality of life (Barlow et al, 2002). The daily tasks requiring self-management are three-fold: (1) taking care of one’s overall health (e.g., healthy eating, being physically active, relaxing and reducing stress, and being knowledgeable about one’s condition, treatments and medications, etc.); (2) carrying on with normal activities and roles in life (e.g., maintaining healthy social relationships and staying involved in home, social, and school/work activities) and; (3) managing the emotional changes that are inherent in the chronic illness experience such as anger, fear, frustration, low mood, etc. (Lorig & Holman, 2003; McGillion LeFort, & Stinson, 2008). To successfully manage these tasks, individuals with chronic health conditions need a set of core self-management skills which include: problem-solving skills; decision-making skills; how to find, evaluate and utilize appropriate resources; how to work effectively in partnership with health care providers and; how to take action to change behavior (McGillion et al., 2008).

Traditional patient education provides information and teaches technical skills about how to manage the chronic condition itself. By contrast, self-management education is broader in scope emphasizing problem solving, action planning for behavior change, and confidence building to enable people to better deal with everyday problems that result from chronic conditions (McGillion et al., 2008). In other words, self-management education helps people with a chronic condition better manage their lives. Self-management interventions typically encompass information-based material and cognitive-behavioural strategies designed to increase participants’ knowledge, self-efficacy and use of self-management behaviors (see Table 1 for elements of a self-management program for youth). Self-management interventions also involve a collaborative partnership between patients and their health care providers to support at-home management of their disease.

Studies in both adult and paediatric chronic illness have shown that comprehensive interactive

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